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Addressing Intimate Partner Violence in Genetics

Patient Perspectives on Intimate Partner Violence Discussion and/or Disclosure During Genetic
Counseling Sessions

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Abstract

Intimate partner violence (IPV) is a major health concern that has become a nationwide epidemic in the United States (ACOG, 2013). The World Health Organization (WHO) describes IPV as physical, sexual, psychological harm including physical aggression and sexual coercion by a current or former intimate partner (WHO, 2015). Due to the psychosocial depth and nature of discussions within genetic counseling sessions, patients may disclose and/or discuss IPV as it relates to sexual well-being, reproductive and overall health. This study aims to assess the role for IPV screening, counseling and intervention in the genetic counseling practice by investigating the incidence, awareness, experiences and attitudes about IPV among genetic counseling patients. Patients receiving genetic counseling at Montefiore Medical Center in Bronx, New York were anonymously surveyed about personal experiences and perspectives on IPV as a topic of discussion and/or disclosure during a genetic counseling session. Among 60 eligible patients, 50 completed the survey (49 females, 1 male, of which, 5 identified as LGBT) ages 20 to 66. The incidence of IPV in this group was 16% (n=8). The majority of participants had never been asked about IPV by a healthcare provider (n=32; 64.0%), would have felt comfortable answering questions about IPV by their healthcare provider (n=34; 68.0%), and would have felt comfortable answering questions about IPV by their genetic counselor (n=39; 78.0%). Perspectives from all participants, notably those with IPV history, provided tremendous insights as to the role of genetic counselors in IPV screening and highlighted areas for IPV screening and counseling training.

Keywords: intimate partner violence; sexual coercion; reproductive coercion; domestic violence; abuse; unplanned pregnancy; unwanted pregnancy; genetic counseling; genetics

Introduction/Background

Violence between intimate partners is often a dynamic, variable and unique combination of physical, sexual and psychological behavior. Sexual violence includes rape, forced penetration to another party, sexual coercion, unwanted sexual contact and or experiences. Physical violence is a broad type of IPV, which ranges from slapping or pushing to burning or choking. Stalking involves unwanted harassments, threats or tactics prompting safety concerns for the victim. Psychological violence includes aggressive verbal behavior or coercive control to threaten an intimate partner (Black, 2010). In addition to the forms of IPV described, there are certain characteristics of IPV that are unique to the Lesbian, Gay, Bisexual and Transgender (LGBT) community such as the use of “outing” as abuse. Fear of outing is used to induce psychological fear and rejection from an individual’s family, friends and/or police (Ard, 2011).

IPV has been linked to poor health outcomes such as unintended pregnancy and late stage cancer diagnosis, via reproductive and or sexual coercion and minimal screening and/or surveillance, respectively (ACOG, 2013; Bourassa, 2007; Cesario, 2014; Miller, 2015; Miller, 2016; Modesitt, 2006; Moore, 2010). Research on IPV is significantly limited in the field of genetics. It has been reported that individuals with mental retardation (MR), currently referred to as intellectual/learning disabilities (ID/LD), are at an increased risk for sexual abuse. Additionally individuals affected with osteogenesis imperfect (OI), another genetic condition that does not include ID/LD, are often suspected to experience child abuse.(Byers, 2006; Levy 2004; Marlowe, 2002).

While current genetic counseling curricula does not address IPV as a topic, genetic counselors receive formal training in interpersonal, psychosocial and counseling techniques which allows opportunities for educational growth and empowerment for this pressing health issue (ACOG, 2013). Currently, the patient perspective regarding IPV disclosure specifically during genetic counseling sessions is unknown. Insights into the patient perspective and experience surrounding IPV disclosure are essential

for healthcare providers (HCPs) to provide the highest quality of care and adequately address this important topic.

Objective

The purpose of this study is to gauge patient experiences with IPV disclosure and perceptions regarding IPV screening/disclosure during a genetic counseling session. This study will ascertain the incidence of IPV among genetic counseling patients while inquiring about awareness, attitudes and history or current experiences of IPV.

Methods

Study Design

The Institutional Review Boards at both Sarah Lawrence College and Montefiore Medical Center, Albert Einstein College of Medicine approved this study (IRB #2015-5787). As a retrospective longitudinal cohort study, the study was executed as a one time, one group cross-sectional design.

Sample

Participants who received genetic counseling in the Division of Reproductive and Medical Genetics at Montefiore Medical Center (Bronx, New York) were recruited following the conclusion of their genetic counseling session by the research team, which included a student researcher from Sarah Lawrence College, board certified genetic counselors and attending physicians within the Division. In order to protect anonymity, information regarding race, ethnicity and socioeconomic status was not collected. According to the 2015 estimation from the United States Census Bureau, the Bronx county population is 1,455,444 and demographics of race included White alone 45.5%, Black or African American 43.5%, American Indian or Alaskan Native 2.9%, Asian 4.4%, two or more races 3.3% and Hispanic or Latino 54.8%. Furthermore, 15.6% of the population were under the age of 65 without health coverage. Recruitment was performed with the study goal of 50 enrolled participants for a satisfactory power analysis of survey responses.

Inclusion Criteria

Patients were eligible to participate if they fulfilled the following criteria: minimum of 18 years of age, English fluency and literacy or Spanish fluency and literacy, patients who attended genetic counseling sessions alone (not accompanied by anyone such as a partner, parent, child, friend, etc.).

Survey

A printed survey containing 25 items was developed by the research team to ascertain the attitudes, comfort level and experiences with IPV screening and/or discussion with HCPs including genetic counselors (Table 1). The survey consisted of eight categories of information: demographics (3 items), indication for genetic counseling and personal health (4), incidence, attitudes and comfort level with IPV screening from a HCP (4), history and experience with IPV (3), history, experience and comfort level with IPV discussion (4), incidence, attitudes and comfort level with IPV screening from genetic counselors (5), IPV in genetic counseling session scenario (1) and an open comment section about IPV (1). Questions varied in format including fill-in-the-blank, multiple choice, and a series of prospective and retrospective statements provided with a five point Likert scale ordinal responses ranging from strongly disagree to strongly agree.

Due to the sensitive nature of the study's topic (IPV), the survey could potentially cause participant distress. The genetics team was available to make referrals to a social worker or other healthcare professional at Montefiore Medical Center if necessary.

Procedures/Data Collection Methods

During a one-hour training session, the research team was trained in recruitment and oral consent. Recruitment was conducted between January 28, 2016 through March 9, 2016. To obtain oral consent, a script was used to highlight pertinent information such as the definition of IPV, anonymity of the survey and overall benefits and limitations of the study. All study materials were kept in two private cubicles which included a locked dropbox for completed surveys, English and Spanish versions of the oral scripts,

blank English and Spanish surveys and safety cards with hotline numbers and applicable resources within New York City. During the recruitment period, patients who declined participation were asked to indicate the reason for declination on the oral script information sheet and placed into the locked dropbox.

Patients who consented to participate in the study were escorted to a private cubicle where they completed the survey. Upon completion, the patient submitted the survey into the locked dropbox.

Data Analysis

Survey responses below 50% were omitted and not included in the data analysis. Quantitative data was analyzed using frequency distributions through Statistical Package for the Social Science (SPSS). Frequency calculations on all data within this sample population included demographics, incidence of IPV and impact of IPV were calculated and reported. Qualitative data analysis was performed through identification of emerging themes from responses to the final survey question which provided an open space for any comments and/or perspectives about IPV. Responses were read by two members of the research team for qualitative analysis and interpretation for common and/or significant themes.

Results

Demographics

Of 60 eligible participants, 50 (83.33% participated) consented and completed the survey, 8 (13.33%) declined and 2 (3.33%) consented to participate but submitted an incomplete survey. The overall response rate from eligible patients was 86.67%.

Demographic information included age, sex, LGBT identity, primary indication for the genetics visit and health information (Table 2). The age range of the 49 respondents (1 participant did not provide an age response) was 20 to 66 years old with a mean of 34.4 years. The majority of participants were female (n=49; 98.0%). Of the 50 participants, 5 (10.0%) identified as part of the LGBT community.

The primary reason for the genetic counseling appointment was reported as: pregnancy (n=35; 70.0%), preconception (n=1; 2.0%), personal history of cancer (n=6; 12.0%), family history of cancer (n=6; 12.0%) and other (n=2; 4.0%). Of the 35 pregnant women, 12 (34.3%) indicated their current pregnancy was unplanned and/or unwanted. Of the 6 participants diagnosed with cancer, the location of the cancer at initial diagnosis was: 1 breast, 1 colon, 1 uterus, 1 ovary, 1 stomach and uterus and 1 declined to answer. Additionally, of these 6 participants, 3 (50%) participants were initially diagnosed at stage one, 2 (30%) participants at stage three and 1 (20%) declined to answer.

Perceptions on IPV Discussion

Of the 50 participants, 8 (16.0%) indicated they felt they experienced IPV in their lifetime while 2 (4.0%) did not know and/or remember, 38 (76.0%) indicated they did not, and 2 (4.0%) declined to answer. Of the 8 participants who felt they experienced IPV, 4 indicated their experience was with one partner, 3 with two partners and 1 with more than five partners. Of the 8 participants who screened positive for IPV, 6 (75.0%) indicated the sex of the abusive intimate partner was male, 1 (10.0%) was female and 1 (10.0%) with both male and female intimate partners. Of the 2 participants who did not know and/or remember, both indicated a male abusive intimate partner.

Regarding whether a healthcare provider had ever asked about IPV during their lifetime, 14 of 50 (28.0%) participants indicated “yes”, 32 of 50 (64.0%) indicated “no” and 4 (8.0%) of 50 did not respond. Those who indicated “yes” identified what type of provider had inquired about IPV in an open text responses: 6 were asked by a nurse, 4 by a physician, 1 by a psychotherapist and 3 did not provide a response. The 14 participants who had received IPV screening were asked to provide a response to the following statement: “I felt comfortable answering questions by my healthcare provider about IPV.” However, the number of respondents to this question (n=27) did not match the number who indicated they had been asked about IPV from a HCP. This may be attributed to the survey design and/or participant miscomprehension. Therefore, this question was omitted from analysis. Participants who had not been

asked about IPV from a HCP were directed to the following statement: “I would have felt comfortable answering questions by my healthcare provider about IPV.” 46 responded with 17 (37.0%) strongly agree, 17 (37.0%) agree, 11 (23.9%) neutral and 1 (2.2%) disagree.

Regarding whether participants felt it was a good idea for genetic counselors to ask all patients about history of IPV, in a private manner, during a session. Of the 50 participants, 15 (30.0%) strongly agreed, 20 (40.0%) agreed, 5 (10.0%) felt neutral, 3 (6.0%) disagreed and 7 (14.0%) strongly disagreed. All participants were presented with the following statement: “I would have felt comfortable answering questions by my genetic counselor about IPV in a session.” Of the 50 participants, 18 (36.0%) strongly agreed, 21 (42.0%) agreed, 6 (12.0%) neutral, 4 (8.0%) disagreed and 1 (2.0%) declined to answer. To gauge patient comfort level with IPV discussion with genetic counselors, participants were asked to respond to the following statement: “In today’s genetic counseling session, I would have felt comfortable discussing my experiences with IPV with my genetic counselor.” Of the 50 participants, 6 (12.0%) strongly agreed, 15 (30.0%) agreed, 12 (24.0%) felt neutral, 4 (8.0%) disagreed and 13 (26.0%) declined to answer.

Participants were presented with an IPV and genetic counseling session scenario involving a patient, Maria. Various reasons and an open text “other” response were provided for participants to identify the reasons they felt why Maria did not disclose and/or discuss her IPV experience (Figure 1). Multiple responses were allowed. “Other” responses from five participants included: “She wasn’t asked. It really wasn’t a topic of discussion”, “I’m not sure genetic counseling is the place to discuss this, maybe in [an] obstetrician’s office? Don’t see the relation”, “Unrelated information”, “I do feel comfortable discussing IPV” and “She might be scared to talk to anyone about it.”

IPV Beliefs

The survey also provided an open response section to share any comments, thoughts and perspectives on IPV. Of the 50 participants, 9 participants provided free text responses which revealed

three themes of insight. First, of the 9 participants, 4 provided the following responses promoting discussion, resources and healthcare for IPV treatment and prevention: “I think [this is] a topic that should be discussed more and more resources should be available...”, “I think healthcare providers should be involved on this topic more”, “I think that this is a very good idea. It can help so many...” and “It would be great if all doctors asked about IPV...” Secondly, the desire of the participants themselves to help victims of IPV also emerged as seen in the following statements: “I do not have these experiences however I am willing to assist others who are experiencing violence”, “At some point I would like to learn to give advice to people who need it...if at some point [they] need my help, I'll be there” and “Don't ever be afraid to speak up or to speak to someone just in case something happens to you.” Lastly, 3 of the 9 respondents highlight the transcendence of IPV as a topic beyond the medical community and provided insight into the social barriers to disclosure: “Intimate partner violence is underreported and our church is actually helping church members to seek help”, “I think IPV is wrong to either of the spouses, but it all depends on one's cultural view of what is acceptable. I believe violence is not accepted in any culture but if one has to depend on the other spouse, the victim will have to continuously stand the risk of IPV because he/she don't want to lose his/her source of support. It also depends on couple's maturity and upbringing. (e.g. If someone was raised in a home where they witness violence, they may grow up to think it is normal way of life, like a lifestyle thing which in some cases it is difficult to change.)” and “The system (police) is not a good one. My own personal experience make[s] you believe you have no help options and it's difficult to want to seek help, in fear that the process is not helpful.”

Perceptions From Individuals With IPV Experience

All 8 participants who revealed experiencing IPV were female and indicated current personal pregnancy as their reason for their genetics appointment. Of these 8 participants, 3 (37.5%) identified as part of the LGBT community. Additionally, 2 of the 8 (25.0%) indicated their pregnancy was unplanned and/or unwanted. Of these 8 participants, 2 (25.0%) indicated they had been asked about IPV by a HCP

in their lifetime. Of these 2 participants, 1 indicated this took place in 2014 in a gynecological clinic with a nurse and 1 indicated this took place at her yearly visit at her primary care physician's office with a nurse. Furthermore, none of these 8 participants had discussed their experiences of IPV within a healthcare setting. All Likert scale questions and responses from these 8 participants are outlined in Figure 2. In the scenario given in the survey, the top three barriers for Maria to discuss and/or disclose IPV within her genetic counseling session identified by these 8 individuals matched those identified by the majority of participants. Of these 8 participants, 4 provided open comments which presented all three themes derived from the responses of all 9 participants who provided open comments.

Discussion

Despite the perceived social stigma of IPV discussion, the majority of all 50 participants would have felt comfortable to discuss IPV with their genetic counselor. This is tremendous insight as HCPs, particularly genetic counselors, can provide encouragement and reassurance for patients to disclose and/or discuss IPV. Creating a safe environment such as displaying a clearly stated policy to respect the privacy of the patient in the waiting room may serve as a subtle encouragement to ask for a private discussion (Miller 2015; Miller, 2016). Previous research has found that women with a history of IPV were 4 times more likely to make a change for the better if discussed with a HCP (Miller 2015; Miller 2016). This underscores the need for appropriate training and education for genetic counselors to screen and provide appropriate care when disclosure is made.

Unfortunately, there are several key barriers to consider related to IPV disclosure that were identified. HCPs may not identify IPV discussion, intervention and prevention as a part of their role. Several studies have presented lack of compliance from HCPs to the recommended universal IPV screening (Waalén, 2000). Results of this study are consistent as only 28.0% (n=14) of participants indicated being asked about IPV by a HCP during their lifetime. The majority of participants reported they were asked by their nurse or doctor at an appointment. In comparison to genetic counselors, nurses

and doctors likely serve in settings where follow up visits with their patients are longer and more frequent throughout their care. This may establish a higher level of rapport for discussion and/or disclosure of sensitive topics such as IPV. Responses to Maria's scenario in this study supports this as the majority of participants (n=29; 58.0%) identified first time meeting a genetic counselor as a main barrier for IPV discussion and/or disclosure. Genetic counselors who serve in pediatric settings likely experience similar routine follow up health care visits with their patients and thus may have higher rates of IPV discussion and/or disclosure.

Along with issues of patient-provider familiarity, fear of medical documentation and fear of others learning of IPV disclosure were identified as barriers to IPV discussion. While genetic counselors cannot eliminate these challenges, genetic counselors can provide a safe, welcoming, and private environment that encourages open discussion. Genetic counselors receive formalized training in contracting, interpersonal, psychosocial patient-centered counseling and support and, therefore, it seems as though there is opportunity to integrate IPV screening into their clinical practice.

The free response statements highlighted patient desire for increased IPV awareness/discussion and recognized the crucial role HCPs can fulfill for the cause. Participants also acknowledged that IPV discussion, prevention and treatment requires a great effort by offering themselves as resources to those in need. Finally, statements provided insight into potential social barriers for IPV disclosure and/or discussion and identify the need for further exploration of psychosocial and other social barriers. The role of religious/cultural institutions was raised, including mention of church, suggesting other resources or areas of support that may be available to our patients.

Perceptions From Individuals with IPV Experience

The incidence of IPV in this sample population was 8 of 50 participants (16.0%) compared to the national average reported as 1 in 3 (35.6%) women and 1 in 4 men (28.5%), experience rape, physical violence, or stalking by an intimate partner during their lives (Black, 2010). The lower report rate found

in this study is likely due to the previously mentioned under reported incidence in healthcare settings due to various HCP and patient barriers. Interestingly, 3 of these 8 participants also indicated identification as LGBT, a population which IPV has been noted to be prevalent (Ard, 2011). Also, all 8 participants also indicated current pregnancy as their primary reason for their visit. This mirrors the population seen at the recruitment site, which is a subset of clinical diagnoses seen by genetic counselors.

The majority of these 8 participants felt neutral or positive about their comfort level discussing their experiences with IPV with anyone (Figure 2). For those who were asked about IPV from HCPs, a substantial number felt comfortable with the discussion. Those who were not asked about IPV from HCPs, 50% would feel comfortable asked by HCPs. Interestingly, 75% would feel comfortable if they were asked about IPV in a genetic counseling session. Furthermore, the majority also agreed they would have felt comfortable discussing IPV with their genetic counselor whom they met with before enrollment in this study. This data shows a positive shift in comfort level towards genetic counselors and supports IPV discussion in this clinical interaction. Furthermore, 25% wished they were asked by a HCP to discuss their experiences with IPV while 50% wished they were given the opportunity by their genetic counselor to discuss their experiences with IPV. Again, the internal desire to discuss experiences of IPV is observed towards genetic counselors. The majority of these 8 participants also agreed with the IPV universal screening recommendation, particularly for genetic counselors. Although relatively small in number, the incidence and invaluable insight observed in this group warrants further exploration for genetic counselors to fulfill a role in IPV discussion and possibly intervention.

Study Limitations

This sample population represents only a subset of clinical diagnosis for which patients receive genetic counseling. There may be IPV related issues of other populations such as pediatric genetics or neurogenetics that may not be congruent with the population under investigation. Furthermore, this targeted sample population lacked the male patient perspective. Lastly, all participants were recruited

from a single medical institution and therefore may not represent the general population as a whole. While important for privacy reasons, the fact that patients were only included if they were not accompanied by someone else impacted enrollment and may have introduced selection bias. For example, genetic counseling patients returning for an invasive prenatal diagnostic procedure are likely and recommended to be accompanied by someone.

Personal time constraints was the primary reason for declining participation. Additionally, individuals may have declined simply due to disinterest on the subject of IPV. It is also important to note that the nature or indication of the visit may have significantly impacted the patient's decision to participate. For instance, consider recruitment of a pregnant woman referred directly from radiology for multiple abnormal ultrasound findings versus an unaffected individual referred for a family history of pancreatic cancer. Both scenarios are indications for a genetic counseling visit but likely present with different levels of stress and anxiety, impacting decision to participate and/or survey completion. The patient demographics for those who declined to participate did not differ from those who consented to participate in the study.

A limitation identified within the survey was observed. A significant number of participants (n=13; 26.0%) did not provide a response when asked about their comfort level discussing experiences of IPV with their genetic counselor. Possible reasons for this include a follow up appointment scheduled with their genetic counselor with discomfort of further discussion. Other reasons include the genetic counselor's involvement in the recruitment and/or consenting process which may have created unintentional pressure and discomfort.

Implications for Practice: Considerations for Genetic Counselors

The negative health impact of IPV has been observed in reproductive settings. Reproductive coercion and sexual coercion are characteristics of IPV which are pregnancy pressure techniques used to alter the pregnancy outcome between an individual and their partner (Miller, 2015; Miller 2016). This

study revealed 12 (34.3%) of the 35 participants indicated their current pregnancy was unplanned and/or unwanted. Furthermore, women who experience IPV are at an increased risk to seek terminations (Bourassa, 2007). It is critical for genetic counselors, who are in the position of collecting and discussing personal medical and pregnancy history with patients, to understand the correlation between multiple elective abortions and IPV that may be disclosed during the counseling session.

Recommendations and suggestions have been made for HCPs to establish effective IPV screening and intervention protocols which genetic counselors may utilize. As previously mentioned, creating a safe environment for patients is key in welcoming discussion about IPV by displaying posters, brochures and safety cards about IPV which may compel the patient to inquire about IPV resources (Miller, 2015; Miller, 2016). Depending on the genetic counselor's space within their area of practice, incorporating these materials where possible may welcome a conversation with a potential victim seeking help. Next, it is important for HCPs to familiarize and disclose any limitations on confidentiality and mandatory reporting legal requirements according to state and federal privacy laws prior to IPV discussion (ACOG, 2013). In this instance, patients may be deterred from hosting discussion of IPV (Gielen, 2000). Unfortunately, this is a legal issue and significant barrier that HCPs cannot influence. Additionally, should a language barrier be present, it is recommended to utilize a medical interpreter rather than a family member or friend for maximized safety. All IPV screening should be performed in a private setting while other persons may be asked to wait in the waiting room during an examination or the patient to be sent alone to phlebotomy (Grace, 2016). Privacy is of utmost importance to maximize confidentiality and effective counseling and aid for the potential victim.

Although each of the identified barriers cannot be eliminated by genetic counselors, each can be minimized by increasing patient rapport, autonomy and empowerment. The first step to establish a plan of action is IPV disclosure from the patient which requires certain language, terms and counseling techniques with a non-judgmental, non-directive and supportive tone to help empower the patient and

encourage open and safe discussion (Table 3). Additionally, open-ended questions and patient-centered communication is essential in the readiness model for IPV and reproductive screening (Miller, 2015; Miller 2016). Genetic counselors, especially those specialized in prenatal and reproductive care, may utilize these suggestions into their practice. Interestingly, crisis counseling is strongly recommended for prospective students interested in genetic counseling and aligns with the values of combating IPV. With a foundation in counseling techniques and crisis counseling experience, genetic counselors are prime candidates to begin the IPV discussion. Genetic counselors also work in an environment where privacy and discussion of sensitive material is common. This serves as a powerful platform for IPV screening and discussion.

Once identified, IPV intervention from genetic counselors can include services, tools and resources. HCPs may offer tools such as the office phone to call resources such as domestic violence (DV) shelters and national hotlines to avoid detection on personal devices (Miller 2015; Miller 2016). Another technique campaigned by Futures Without Violence is the use of a palm sized safety card to provide to the victim. Safety cards include self-assessment questions and safety planning strategies and resources to aid the patient and HCPs in IPV identification and screening. These wallet-sized cards can be reviewed between HCP and patient in under a minute and have shown to effectively reduce odds of pregnancy pressures and coercion at follow up (Chamberlain, 2012). Utilizing the private setting of a genetic counselor's office, these tools and resources can be incorporated into sessions between genetic counselor and patient. Lastly, immediate referrals may be made to an advocate, social worker, shelter or police who specialize in cases of IPV. In order for this technique to be effective, HCPs are encouraged to coordinate policy decisions and an approach to prevent and address IPV with local resources such as women's organizations and authorities (Ramsay, 2002). Any HCP, including genetic counselors, may reach out to local resources such as specialized shelters (women, LGBTQ, etc), counseling, specific support groups and alliances to establish a protocol for referral. Posting a list of updated contact

information in clinic waiting rooms and/or exam rooms may also serve as an alternative. With the appropriate IPV education, training and resources, genetic counselors can be an integral part in addressing this national crisis.

Implications for Future Research

To address the gender bias of IPV disclosure, IPV screening and/or discussion for HCPs who primarily treat the male population is critical. As an example, similar to OB/GYN doctors for women, targeting urologists as a strategic position for IPV discussion with men should be considered. As HCPs, it is important to establish a mentality of outreach to areas where potential victims may greatly benefit and/or potentially be life saving. Interestingly, this study also provides insight into other areas beyond the medical community where IPV discussion and/or disclosure can be facilitated such as churches and other community centered organizations. This insight speaks to IPV as a health crisis that transcends the medical field into other areas of health and wellness. This also highlights the importance of a multidisciplinary approach to prevent and combat IPV such as partnerships between community-based programs and medical facilities.

Lack of healthcare utilization has been observed in oncology settings. Victims of IPV often avoid gynecologic care due to association with sexual violation and are therefore diagnosed with advanced stages of gynecological cancers (Modesitt, 2006). In this study, 2 (30%) participants were initially diagnosed with advanced (stage three) breast and colon cancer, respectively. Although review of the literature suggests reported late stage cancer diagnosis and location of cancer in relationship to a history of violence, the sample size is not large enough to make a significant correlation. Further research is needed for IPV discussion with HCPs within the oncology setting.

Genetic counselors should be familiar with mandated reporting laws within their state of practice and most cases of suspected abuse often involve a referral for child protective services (CPS) and adult protective services (APS) with optional national hotline (1(800)-4-A-CHILD) and local law enforcement

(Byers, 2006; Levy 2004; Marlowe, 2002). It is important to note, while these are informative recommendations, IPV training in the genetic counseling profession is not widely provided. In contrast to victims of IPV, disclosure of child abuse from a victim may be higher due to factors such as likelihood to state pain, which may be encountered by genetic counselors specialized in pediatrics and requires further research. Aside from research within these two high-risk populations, this study is the first to our knowledge to address abuse and violence in other vulnerable populations genetic counselors frequently encounter in clinic such as pregnant women, women who experience multiple miscarriages and cancer patients.

Genetic counselors are in a unique position to offer, support and even implement screening and interventions for IPV. Although the topic of abuse is noted in genetic counseling literature, standards for IPV screening and interventions are currently not well established in the field of genetic clinical practice. The results from this study introduce the need for incorporating techniques and tools currently available in the healthcare industry, specifically, in a clinical genetics setting. It is possible that IPV prevention tools and techniques, such as easily accessible safety cards, brochures, signage and poster displays, are currently available in the genetic counseling setting and warrants further study. This important piece will be investigated by the concurrent genetic counselor's perspective on IPV discussion and/or disclosure study.

Conclusion

IPV is a preventative health issue that has grown into a crisis in the United States. The consequences of IPV are physically and mentally damaging and in a significant number of cases, fatal. Significant health issues associated with IPV have the potential to be prevented or resolved in a healthcare setting. Genetic counselors will encounter victims of IPV in their professional setting. It is, however, important to consider the barriers, challenges and patient screening preferences to establish an effective protocol for IPV screening, prevention and treatment. Although several studies have evaluated both

professional and patient perspectives on IPV in other healthcare settings, research in the clinical genetics setting is significantly limited and requires attention. Since victims of IPV are widespread, implementing an IPV screening and intervention protocol requires consideration for psychosocial dynamics, cultural and societal views and sexual orientation. Genetic counselors encounter patients from all backgrounds and have the capacity to provide help and resources for potential victims.

IPV is often a private issue with the potential to have deeply damaging and fatal consequences for an individual. Perhaps due to the new, specialized, relatively small and growing profession, no studies currently exist assessing the connection between IPV victims and genetic counselors. Patient perspectives on IPV discussion and/or disclosure during genetic counseling sessions serve as the foundation and motivation for a possible integration. The incidence of IPV in the genetic counseling patient population from this study alone reveals strong considerations for genetic counselors to implement extended training in IPV screening, counseling and intervention. It is important to give patients a voice on this issue by promoting a safe and open environment. Patient identification of potential barriers in this study provides valuable information for an effective approach to IPV discussion and intervention for genetic counselors. Genetic counselors hold a unique position to effectively identify, screen, provide tools, educate and advocate for their patients against IPV.

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All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.

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Tables & Figures

Table 1. IPV patient perspective survey

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Demographics	<p>1. How old are you? ____ years old</p> <p>2. What is your gender? (please check one) <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> Transgender Male <input type="checkbox"/> Transgender Female</p> <p>3. Do you think of yourself as part of the LGBT (Lesbian, Gay, Bisexual, Transexual) community? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not know <input type="checkbox"/> I do not want to answer</p>
Indication and personal health	<p>4. Why did you have a genetics appointment today? (Please check one below)</p> <p><input type="checkbox"/> I am pregnant.</p> <p><input type="checkbox"/> I am not pregnant, but am planning for a future pregnancy.</p> <p><input type="checkbox"/> To get my blood drawn because my partner is pregnant (I am the father of the baby).</p> <p><input type="checkbox"/> I have cancer or I have had cancer in the past.</p> <p><input type="checkbox"/> I have a family history of cancer.</p> <p><input type="checkbox"/> Other (please explain) _____</p> <p>5. If you answered "I am pregnant" on question 4, is this an unplanned and/or an unwanted pregnancy? <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not know <input type="checkbox"/> I do not want to answer</p> <p>6. If you answered "I have cancer or I have had cancer in the past" on question 4, where in the body was cancer first diagnosed? For example, was cancer first diagnosed in the breast, ovary, uterus, or prostate?</p> <p>7. If you answered "I have cancer or I have had cancer in the past" on question 4, what stage was the cancer first diagnosed? <input type="checkbox"/> Stage 1 <input type="checkbox"/> Stage 2 <input type="checkbox"/> Stage 3 <input type="checkbox"/> Stage 4 <input type="checkbox"/> I do not know</p>
Incidence, attitudes and comfort level with IPV screening from a HCP	<p>8. Have you ever been asked questions about Intimate Partner Violence by a healthcare provider (for example, from a doctor or nurse)? <input type="checkbox"/> Yes <input type="checkbox"/> No (If you answered "No," please skip to question 11)</p> <p>9. If you answered "Yes" to question 8, please explain below when, where and by whom you were asked about Intimate Partner Violence? *10. Please circle below the best response that represents how you feel about the following statement: I felt comfortable answering questions by my health care providers (such as doctors and/or nurses) about Intimate Partner Violence.</p> <p>*11. Please circle below the best response that represents how you feel about the following statement: I would have been comfortable answering questions by my health care providers (such as doctors and/or nurses) about Intimate Partner Violence.</p>
History and experience with IPV	<p>14. Do you feel that you have experienced Intimate Partner Violence in your lifetime? (please refer to definition at the beginning of the survey) <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not know/I do not remember</p> <p>15. If you answered "Yes" to question 14, in your lifetime how many partners have you experienced Intimate Partner Violence with? <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4 <input type="checkbox"/> 5 <input type="checkbox"/> More than 5 <input type="checkbox"/> I do not know/I do not remember</p> <p>16. If you answered "Yes" to question 14, what gender was your partner? <input type="checkbox"/> Male <input type="checkbox"/> Female <input type="checkbox"/> I have experienced Intimate Partner Violence with both male and female partners.</p>
History, experience and comfort level with IPV discussion	<p>17. Have you discussed experiences of Intimate Partner Violence while in a healthcare setting in your lifetime? (Example: at a GYN appointment, in the emergency room, or to your family doctor or nurse) <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> I do not know/I do not remember</p> <p>18. If you answered "Yes" to question 17, please explain when, where and to whom did you discuss experiencing Intimate Partner Violence in a healthcare setting? *19. Please circle below the best response that represents how you feel about the following statement: I do not feel comfortable discussing my experiences with Intimate Partner Violence with anyone.</p> <p>*20. Please circle below the best response that represents how you feel about the following statement: I wish I was given the opportunity by a healthcare provider to discuss my experiences with Intimate Partner Violence.</p>
Incidence, attitudes and comfort level with IPV screening from genetic counselors	<p>*12. Please circle below the best response that represents how you feel about the following statement: I think it is a good idea for genetic counselors to ask all patients about a history of Intimate Partner Violence, in a private manner, during a genetic counseling session.</p> <p>*13. Please circle below the best response that represents how you feel about the following statement: I would have been comfortable answering questions by my genetic counselor about Intimate Partner Violence during my genetic counseling session.</p> <p>*21. Please circle below the best response that represents how you feel about the following statement: I wish I was given the opportunity by my genetic counselor to discuss my experiences with Intimate Partner Violence.</p> <p>22. Did you discuss Intimate Partner Violence with your genetic counselor in today's genetic counseling session? <input type="checkbox"/> Yes <input type="checkbox"/> No (If you answer "Yes," please skip to question 24)</p> <p>*23. Please circle below the best response that represents how you feel about the following statement: In today's genetic counseling session, I would have felt comfortable discussing my experiences with Intimate Partner Violence with my genetic counselor.</p>
IPV in genetic counseling scenario	<p>24. Please read the scenario below.</p> <p>Maria is a 36 year old woman who has experienced Intimate Partner Violence is seen for a genetic counseling appointment but does not talk to the genetic counselor about her experiences with Intimate Partner Violence.</p> <p>Based on your personal experience with genetic counseling from today's genetic counseling session, what are some reasons you think that the 36 year old woman did not talk about her Intimate Partner Violence with her genetic counselor? Please check all that apply. (IPV= Intimate Partner Violence)</p> <p><input type="checkbox"/> She did not feel comfortable discussing IPV with the genetic counselor because of his/her gender.</p> <p><input type="checkbox"/> She did not feel comfortable discussing IPV with the genetic counselor because of his/her age.</p> <p><input type="checkbox"/> She did not feel comfortable discussing IPV with the genetic counselor because it was her first time meeting him/her</p> <p><input type="checkbox"/> She did not feel comfortable discussing IPV with the genetic counselor because of a language barrier/using an interpreter.</p> <p><input type="checkbox"/> She did not have enough time in the session: too much information to discuss with the genetic counselor</p>

	<input type="checkbox"/> She did not have enough time outside of the session: another appointment after the genetic counseling appointment, pick up child from school, or other commitment <input type="checkbox"/> She fears her significant other will learn this information <input type="checkbox"/> She fears that another health care provider (doctor, nurse) will learn this information <input type="checkbox"/> She fears this information will be recorded in her medical records <input type="checkbox"/> Other: _____
Free text section	25. If you have any other comments or if there is anything else you would like to share about the topic of Intimate Partner Violence, please explain in the space below.
	*Questions provided with Likert scale responses: strongly agree, agree, neutral, disagree, strongly disagree

Table 2: Respondent demographics

Variable	n	%
N= 50		
Mean age	34.4	
N= 50		
Gender		
Male	1	2
Female	49	98
Transgender Male	0	0
Transgender Female	0	0
N= 50		
LGBT status		
Yes	5	10
No	43	86
I do not know	1	2
I do not want to answer	1	2
N= 50		
Primary indication for visit		
I am pregnant	35	70
Preconception	1	2
Blood draw for partner's pregnancy (father of the baby)	0	0
I have cancer or history of cancer	6	12
I have a family history of cancer	6	12
Other	2	4

Table 3. Compilation: Suggested counseling language & sample screening questions

I'm really glad you came in today (fill in the blank for visit type). Before we get started I want you to know that everything you share with me is confidential, unless (fill in state law here—likely this script will look very different for an adolescent than an adult)—those things I would have to report, ok? (Chamberlain, 2012)
Normalizing language such as “unwanted or forced sex” rather than “rape” (ACOG, 2013)
Are you ever afraid of your partner? (Waalens, 2000)
(Once positively screened) This could be important information for your health care. Would you like help with any of this now? (Waalens, 2000)
Some women tell us their partners are pressuring them to get pregnant. Have you experienced something like that? (Grace, 2016)
Has your partner ever forced you to do something sexually you did not want to do or refused your request to use condoms? (Grace, 2016)
Has your partner ever tampered with your birth control? (Grace, 2016)

Are you worried your partner will hurt you if you do not do what he/she wants with the pregnancy? (Grace, 2016)

Does your partner support your decision about when or if you want to become pregnant? (Grace, 2016)

Figure 1. Maria's scenario exercise: number of patients who identified possible barriers

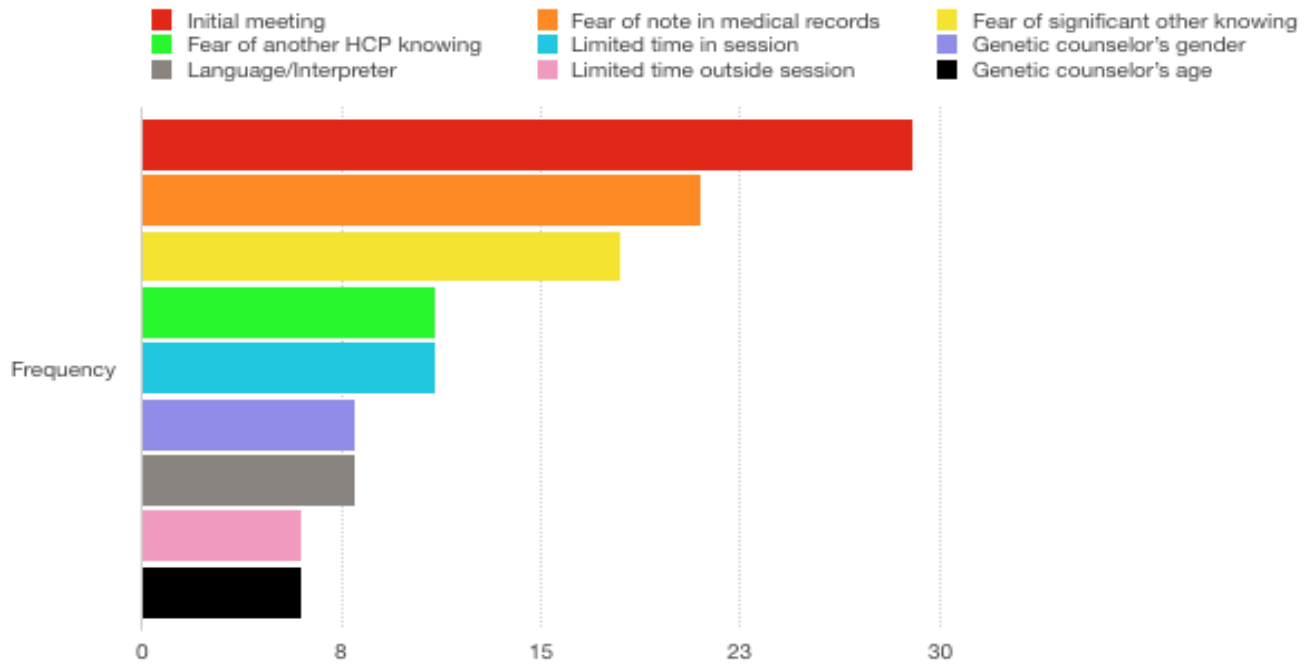


Figure 2. Percentage of responses from participants who revealed personal history of IPV (n=8)

